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ABSTRACT

The booklet contains proceedings of a 1982 conference focusing on the needs of parents of handicapped children. Summaries of presentations and panels address the following topics: federal support systems for parents of handicapped children, parents' reactions to learning their child is disabled, early intervention services, community support systems and advocacy programs, improvement of family relationships, recognition of psychological needs of handicapped children, recreational and leisure time opportunities, parents' role in the intervention program, coping skills effective for parenting, visual impairment, and evaluation of the conference and parent suggestions. Emphasis is on such Nevada programs as the Coalition for Handicapped Children's Education, the Developmental Disabilities Advocate's Office, Northern Nevada Mental Retardation Services, Mayville Counseling and Psychological Services, and Southern Nevada Association for the Handicapped. (SW)

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We Can Do It Together!

Coping Skills and Resources for Parents of Handicapped Children

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WE CAN DO IT TOGETHER!

Coping Skills and Resources for Parents of Handicapped Children

The program was focused on the needs of parents of special children----- those children who have physical, mental or emotional disabilities. It was intended for parents; special educators; medical, psychological, social service personnel and others interested in services for the child with a disability.

The conference was designed to inform parents of the support that is available for coping with the problems that develop when special children are part of the family. Parents learned how to create quality family life for all family members, develop an awareness of community resources, recognize individual and community needs for support systems, and develop coping skills for effective parenting. The intent of the conference was to initiate an ongoing community support system for parents of special children.

The program was partially funded by a grant of the Nevada Department of Education, Special Education Programs.

Sponsors: CHANCE - Coalition for Handicapped Children's Education
Continuing Education, University of Nevada Reno
Governor's Committee on Employment of the Handicapped
Nevada Department of Education, Special Education Programs
Nevada State Federation of the Council for Exceptional Children

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INTRODUCTION by Kathleen E. Olson, Executive Director
Governor's Committee on the Employment of the Handicapped

It gives me a great deal of pleasure to introduce Kathy List, the First Lady of our great state of Nevada. Mrs. List has been a great advocate for the disabled and she has been involved in many of our programs over the past few years. Last year she and the Governor received over 200 children with disabilities at the Governor's Mansion. The children enjoyed music and lunch. They saw clowns and musicians perform. Each child received the state seal directly from Governor and Mrs. List. They were able to talk to the Governor and Kathy and were interested in the Governor's family.

Kathy List has traveled around the state to visit programs and facilities which were established for the disabled. She has been supportive of our programs and we are extremely fortunate to have her join us today.

WELCOME - Mrs. Kathy List, First Lady of the State of Nevada

I'm pleased to be a part of this very special conference concerning assistance for Parents of Handicapped Children. As a former teacher and as a parent, I've always been interested in children. The uniqueness of these very special children is a challenge to the parents and to the agencies and organizations assisting them. The conference title, "WE CAN DO IT TOGETHER!," is right on target because it's very true that searching alone can be difficult, but with a little help we can set a goal and strive to meet it. There are realistic goals; there are dreams to realize; there is a future for children with disabilities. Our state agencies have set a good track record and we hope to expand those programs to assist all of you with your difficult, but reachable, goals. Parents hold in their hands the keys to the future of their children. It is natural for you to be concerned and by sharing information with others, you can better understand your child's condition so that, in turn, you can help him or her deal with it.

1982 is the National Year of the Disabled Person. During this year we hope to focus on positive programs already developed for persons with disabilities. Also, we are looking to implement new, innovative programs which point to the abilities of the disabled and which will expand our resources to serve them better.

I'm delighted that you invited me to participate with you here today and I look forward to a very rewarding learning experience. I am hopeful that this conference will change your lives. We will work with you to make that happen. You have my very best wishes for a very productive and successful meeting.

INTRODUCTION by Kathleen E. Olson, Executive Director
Governor's Committee on the Employment of the Handicapped

I'm honored today to introduce to you the Honorable Senator Howard Cannon of Nevada who ranks number seven in the U.S. Senate. Senator Cannon has protected the rights of the disabled during his years in the Senate and has been a staunch supporter of Rehabilitation legislation and funding for programs concerning the disabled.

In a recent letter to President Reagan, Senator Cannon joined his colleagues in calling upon the President to continue his support for guaranteeing that each handicapped child in America be provided a free, appropriate public education.

Senator Cannon continues to assist us with our programs and I'm happy that he has taken time out of his busy schedule to address this conference.

FEDERAL SUPPORT SYSTEMS FOR PARENTS OF HANDICAPPED CHILDREN

Senator Howard Cannon

Great strides have been made over the last five years to recognize and protect the rights of handicapped persons. Unfortunately, these accomplishments are currently being threatened by the Administration in Washington and its supporters who are advocating extreme budget cuts and legislative changes in many program areas affecting the handicapped.

Nowhere is this more obvious than in the area of education for the handicapped, which must be of tremendous concern to you as parents of handicapped children. The Administration is in the process of revamping an entire spectrum of educational services, reorganizing them into one large state block grant program which will result in less funds and fewer guarantees of rights. The general position being taken by the administration is that cost should be a primary factor of consideration and that handicapped children should be mainstreamed into regular classrooms as much as possible.

I believe that these are steps being taken in the wrong direction. As an original cosponsor of the Education for All Handicapped Children Act, I joined several other Senators on February 4th of this year in sending a letter to the President urging him to support full funding of the program and to oppose substantive changes in the law.

I will continue to do my part in Washington by closely scrutinizing and opposing administration budget cuts and program revisions which affect the handicapped. But I need your help. I urge you to continue to take advantage of conferences such as these to learn to be effective advocates for your children. We must work together, now more than ever, to maintain and protect the gains we have made thus far in our fight for the rights of handicapped persons.

PREFACE

Kathleen E. Olson, Executive Director
Governor's Committee on the Employment of the Handicapped

It's always a shock for a family to learn that their child has a disability. However, out of the initial shock and dismay can be built a loving, understanding and accepting environment in which the child can grow in self-confidence, secure in love, and belief in his/her own ability to succeed.

The way a child learns to think about himself/herself and the disability has a great deal to do with the kind of person he/she becomes in later life. If the child is anxious, fearful and sheltered from the outside world, and feels the disability is the dominant feature of life, he/she will become dependent and immature during childhood and in later life.

If the child treats the disability as an inconvenience and joins in daily activities with other children in the community or at home, he/she has a better chance of growing into a secure and independent person. Early confidence will help the child cope with the ignorance of others and to develop his/her own potential.

Like most parents, you're concerned about the future. You wonder about your child's achievements at school, or in the future. You hesitate to discipline the child or let him/her "rough house" with the family.

You may find it difficult to talk about or accept the disability. You may get upset for reasons that you find hard to explain. There may be family tension and you don't know where to turn. If you speak to the doctor about your child's condition you may find that you can't really follow what he is saying. You may feel angry, depressed, inadequate - even guilty. Perhaps you feel that in some way you have failed as a parent.

These are normal reactions to the situation and they are temporary. After awhile these feelings pass, the family pulls together and everyone concentrates their energies on helping the child.

Both parents should be involved in matters concerning the child. As you learn more you become more at ease. By both parents being equally involved, the child has additional support and the family moves in the same direction. A realistic, optimistic "let's see how things go" attitude on the part of parents is probably most encouraging to the child. He/she should be praised for his/her achievements and should be encouraged to do his/her best. He/she should not be placed under so much pressure to achieve that he/she becomes anxious and afraid of failure.

Be straightforward about the disability. A child can create a far more damaging explanation of his condition out of anxiety and confusion than with a simple matter of fact explanation. You will teach your youngster that there is nothing to be ashamed of. The same attitude will help friends and neighbors feel that way too.

You have an excellent opportunity to help everyone become better informed. It takes much love, work, patience, understanding, and confidence but you can help to develop an atmosphere of understanding and acceptance in your community and for your child.

WE CAN DO IT TOGETHER! PARENT PANEL

Moderator: Don Jackson, Ph. D. Community Psychologist
Northern Nevada Mental Retardation Services

Each member of the Parent Panel has had unique and personal experience with handicapped children. Their perspectives differ, and the issues they will address differ.

Yet I believe there is a common thread to the perspectives you will hear, and that is "normalcy" - - having the child be a part of a normal family and community situation. This is a very difficult balancing act at times, that of getting special needs of the child addressed and attended to while keeping things "regular."

Each member of the audience as well has very specific reasons for being here, having lived with, taught, treated or in other ways having seen to the needs of children with special needs. Each participant in the workshop, no doubt, has particular priorities at this time, and as needs change, so will these priorities. As the purpose of this conference is "to initiate an on-going community support system for parents of special children," we want to give voice to the audience's specific comments, concerns and priorities. Hopefully the short comments by the members of the Parent Panel will spark your own thoughts and begin the process of kindling a dialogue between us today.

The first speaker from the Parent Panel is Assemblyman Dave Nicholas. Dave is, of course, a State Assemblyman and a parent with particular concern for the area of developmental disabilities. He is Vice Chairperson of the Nevada Developmental Disabilities Council. He chaired an interim study committee of the Legislature on the needs of adult mentally retarded citizens. I know that he recently returned from a speaking engagement in Washington, D. C. where he addressed the National Association of Developmental Disabilities Councils.

Dave addressed the workshop and spoke about his personal experiences involving a handicapped family member, and went on to share issues that will be addressed in the upcoming State Legislative session:

a) The Equal Rights Commission needs to have its statutory rights broadened to include the mentally retarded.

b) SB268 concerning the prohibition of restrictions on residential placements of mentally retarded citizens needs to be reinstated (It's a "sunset" bill).

c) AB119 -- the Family Preservation Act needs to be reinstated (another "sunset" bill).

d) Proposals will be needed for ways to deal with the impending reduction in federal funds. One idea is to establish a State "facility" bank so that CTC's for example could borrow money at a low interest rate for building facilities for the retarded.

e) Volunteers need the authority to drive state vehicles of agencies they work for.

Our second speaker is Laura Kerin. Laura is a parent of a child with Down's Syndrome. She is the Northern Vice Chairperson for CHANCE -- the Coalition for Handicapped Children's Education, and she serves on the State Exceptional Pupil Advisory Board. Perhaps more than anyone, Laura provides testimony to the fact that one person can make a difference.

Laura spoke about her daughter, Jennifer, and described Jenny as her best friend. She gave examples of the outstanding growth of Jennifer. She also spoke about now she felt she was able to influence the development of special education programs when she came to Nevada in 1975.

The next parent to speak today is Gil Folk. Gil is the Assistant Principal for McQueen High School. He has been the foster parent for Travis, now 13 years old, since he was a toddler. For five years now, Gil has been a single parent.

Gil addressed his comments to the fact that the rewards are great for him, and that as far as he is concerned, there is no such thing as "poor Travis." For Gil, it is simply a matter of raising his son, keeping things as "regular" as possible.

The final member of the Parent Panel is Shirley Martel. Shirley is a Licensed Practical Nurse. She has her own family including three teenagers. But in addition, she operates a group home for four severely to profoundly retarded youngsters between the ages of five and fourteen.

Shirley emphasized the need to have a positive outlook and to stress the fact that these children can learn. She keeps things fun and uses the staff at SDC (Northern Nevada Mental Retardation Services) for her "warm fuzzies."

At this point, there were comments and questions from the audience. If we have achieved our purpose here, we have kindled your thoughts and emotions concerning handicapped children. I wish to thank the members of the Parent Panel for sharing their thoughts and feelings, and I wish to thank the members of the audience for participating by listening and/or speaking.

Assemblyman David Nicholas, Parent

The current economic situation in Nevada parallels that of several dozen other states. We are faced with the chance of a deficit in our State budget. In a recent speech to the National Association of Developmental Disabilities Councils, I suggested that they take this fact into consideration. But it is also evident that funding for the developmental disabilities program will be part of the block grant direction being taken by our national government. As a result, the states will have a greater role to play in funding Developmental Disabilities programs and in determining the funding of most health programs.

Nevada, almost in anticipation of these directions, has been involved in studying some of the problems and directions in training, group-living, etc., of retarded adults. Some of the recommendations of the Legislative Committee, set up to make the study, are as follows:

1. Broaden the statutory responsibility of the state equal rights commission to include the mentally retarded.

2. Extend the provisions of S. B. 268 of the 1981 session, which allow for residential placement.

3. Extend the provisions of the "Family Preservation Act of 1981 (A.B. 119), which provide grants to certain families in order that they may be able to care for their mentally retarded relatives at home.

4. Set up a loan fund that organizations such as C.T.C.s can use for capital expansion.

The Legislative Committee may have correctly assumed a diminishing amount of funds being available in many of their recommendations. The theme of those recommendations generally is, however, that existent programs do not sufficiently meet the public need and should not be cut back even if the funding situation is problematical. Other less critical areas should be dealt with before approaching this area for reduced funding.

Laura Kerin, Parent, Coalition for Handicapped Children's Education
Northern Vice Chairperson

Early intervention services made the critical difference in my daughter's development. Keeping her developmental level on par with her chronological age was so important to us as a family we tapped every imaginable source. We strive for the most normal environment possible for this mildly retarded child. We stress the importance of appropriate behavior, impeccable grooming, and attractive, fashionable clothes. We firmly believe this has contributed to her success in the real world.

A lot of people are due credit for her success; our family, neighbors, friends, a variety of programs, a large number of wonderful teachers and therapists, medical and professional people. But, most of all, Jennifer

is responsible for her success, and we love her for it.

There have been fantastic triumphs and lonely valleys of despair. In all, the experience has added a dimension to all our lives. Jennifer's accomplishments and most of all her courage has given hope to many other parents.

If we could do it over again, what would we change? Well, I'd just like for her to have curly hair.

POSITIVE ATTITUDES WORK

Shirley Martel, Licensed Practical Nurse, Developmental Home Foster Parent

My main thought concerning care and training of the developmentally disabled is that all persons have a right to a happy and full life. I believe they have a right to develop to their potential whatever it may be. The less restrictive the environment the greater the potential.

I believe the developmentally delayed can learn and be socially acceptable. It may take longer, but it can be done.

I believe in setting goals and expecting that they will be attained. These children need demands put on them so they will reach higher. Rewards and love are a must.

I believe in getting the support of family and others. My children are excellent "teachers." I never hesitate to counsel with the social worker, behavior management specialist, nurse, teachers, friends, and other co-workers. They encourage and support my work. Continuity is vital at home and at school for the success of the client.

The person rewards are great as I see them succeed at a new task or a stranger learns to accept a person who is not perfect. We are making progress!

WORKSHOP SESSIONS

I. WE ASKED FOR IT. WE GOT IT!
Community Resource Support Systems and Advocacy Programs

Moderator: Anne W. Clancy, M.P.H. Program Director/ Social Worker
Eagle Valley Children's Home

Webster defines the verb "to advocate" thusly: "to promote the interests or cause of: to support; or to uphold or defend as valid or right." Parents and professional service providers in their mutual, but separate pursuits of deeper understanding, better treatment, and more services for developmentally disabled children have often worked at cross-purposes. Differences in our perspectives have led to unfortunate discrepancies in services and programs. In other words, we have asked for it, but what we got wasn't quite what each one of us wanted or envisioned. Advocacy most often turns out to be criticism of the provider because of the failure of the system to meet the needs of the handicapped. In its most effective form, advocacy becomes the system through which parents and professionals make changes in the whole structure which they have identified as being necessary. What has caused our problems? Why don't we in Nevada have a more effective system? Three major obstacles have subverted our efforts, and these three all arise from problems in communication: confusion, isolation, and ignorance. Professionals in the field have failed to ask themselves how they can make their unique help truly helpful to the parents and less stressful in what already is a stressed,vulnerable situation. Our goal in all advocacy programs should be to foster informed, supportive, effective interactions between all caregivers of handicapped children - parents and professionals. We must transform our current confusion of goals into a mutually arrived at clarity of vision. We must replace our separate cocoons of isolation from each other with reciprocal PARTNERSHIP within which we share and exchange beneficial information toward a common goal. We must erase ignorance with a continual sharing of information. Then we would truly possess a community resource support system for the improvement for the whole treatment realm of our developmentally disabled children.

Holli Elder, Director, Developmental Disabilities Advocate's Office

The Developmental Disabilities Advocate's is an agency providing a variety of services to the disabled in Nevada. The primary function is to advise a handicapped person of his/her legal and individual rights to treatment and services. If anyone has been denied his/her rights, the Advocate's Office will provide individual assistance, representation, and legal aid. The Office also is able to give information on services available in Nevada and is capable of referring a person to the agency best able to meet his/her needs. Assistance is available on all areas of concern including education, employment, transportation and housing. For further information, please call: Holli Elder, Project Director (702)784-6375 or 800-992-5715, toll-free.

Sharon Palmer, Educational Consultant, Nevada Department of Education

The Nevada Department of Education, Special Education Branch, offers a number of services to parents of handicapped children. Funds are provided through subgrants to school districts, State agencies, parent groups, and other organizations to provide training to parents to meet identified needs. We frequently meet with leaders of individual parent groups or Coalition for Handicapped Children's Education to assist in resolving problems or to provide information on the status of special education in Nevada. We respond to individual complaints or requests for due process hearings and assist parents and school districts in resolving disagreements.

A recently concluded two-year project reached parents of young children through television spots and an Early Childhood Totline. Parents could call the special toll-free number to request child development information or discuss concerns with the Early Childhood Consultant.

The Department also develops, prints, and distributes informative documents for parents. The following materials can be acquired free of charge by calling 1-800-992-0900 ext. 3140 or (702,885-3140 or by writing the Nevada Department of Education, Special Education Programs, 400 West King Street, Capitol Complex, Carson City, Nevada 89710

Crib to Kindergarten Wheel
Chart of Normal Development
One Step at a Time
Will Your Child Be Ready
Special Education Rights (Spanish and English)
Evaluation and Confidentiality Rights
Handbook for Parents of Handicapped Children
Early Childhood Special Education Brochure
Directory of Early Childhood Services to Children with Special Needs
Standards for Administration of Special Education Programs

Dennis Hall, Director of Community Services, Northern Nevada Mental Retardation Services

The Northern Nevada Mental Retardation Services as an agency of the Division of Mental Hygiene and Mental Retardation, is responsible for community and residential services for mentally retarded persons living in the 13 northern counties of Nevada.

The Sierra Developmental Center is a 78 bed Intermediate Care Facility for the Mentally Retarded (ICF/MR). The SDC provides 24 hour awake care for those retarded persons who require close supervision and a structured living environment, including medical supports. The facility is located in Sparks and is composed of 6 cottage-type living units (the largest unit accommodates 18 residents, the smallest 8 residents), a separate day training unit and an administrative support unit.

The Community Services Program is responsible for the recruitment, screening, supervision and monitoring of all foster care or group homes serving mentally retarded in the Northern Region. Through the Legislatively created Residential Placement Fund, NNMRS is able to contract with private individuals and corporations to provide out of home living arrangements for mentally retarded clients.

Community Services is also the entry point for anyone in Northern Nevada requesting services for a mentally retarded family member. Client and family counseling and training are available.

ALL social services and case management are the responsibility of Community Services, as is the coordination of respite care, the Family Preservation Project and Community Education. Speakers are available to address groups interested in learning more about available services, trends, and needs.

The entire case management and service delivery system are based on the Interdisciplinary Team process, which involves the case manager, client, parents/guardians, home operator, psychologist, nurse and other professionals as are appropriate. Parents and guardians are encouraged to question the plans developed and challenge the "professionals." The best way to understand a service system, to know what kind of services are available and to assure that your or your child's rights are being upheld is to question. Ask what your rights are as a client of the agency, what are your responsibilities and the agency's responsibilities. Ask why a particular service is not being offered, what is the chain of command and who has authority to respond to your needs.

The parents/guardians and home operators who have taken the time and energy to learn the system and the people in it, have been able to impact some positive changes in service and service delivery.

Consumers of agency services, those who are to benefit from agency intervention at whatever degree are the best advocates for maintaining services, initiating new programs and improving the quality of all services.

We cannot meet your needs if you don't let us know that they are not being met. But you need to know what can be done, how an agency works, what all that "professional jargon" means.

- Don't be embarrassed to ask what clinical, medical, educational or professional terms mean. Ask for a practical example. This will help remind the "professional" to speak English as well!

- Don't allow yourself to be intimidated by the overabundance of acronyms and abbreviations; P.L. 94-142, IEP's, SDC, VR, DTC and D.D.P.A. all are real things that are explainable.

- Become aware of how the agency works, ask for reference material on the laws and policies that have impact on the service you are requesting.

II. RESOLVING FAMILY CONFLICT ----- IMPROVING FAMILY RELATIONSHIPS

Keith Pierce, Ed. D. Professor and Chairperson Counseling and Guidance Personnel Services, University of Nevada Reno

Conflict in families is natural. It is part of living. Learning how to resolve conflict is necessary to have peace in the family, however.

Several attitudes and behaviors are useful in establishing the kinds of relationships which make resolving conflict possible.

Conflict can be minimized when family members help each other belong and have a place of respect and significance within the family.

Individual children must be recognized for their strengths and their desire to succeed. Focus on efforts and small gains. Encourage with positive expectations. Insure rights and privileges for all family members.

Require order and routines, but allow situations to correct and teach. Intervene with consequences that are related to misbehavior. Run from retaliation and "getting even."

Work on communications skills of active listening, "I" statements and negotiation. Talk openly and regularly in family meetings, where plans, problems, solutions and recognition can be considered.

Accompany your family member. Do things with them for fun, for work and for learning.

Resolving conflict and improving relationships in a family requires work and sustained effort.

Success is possible. It is so badly needed.

Jack Mayville, Ph. D. Psychologist, Mayville Counseling and Psychological Services

Conflict resolution within the family context must be addressed in a systematic, consistent and objective manner. Initial focus should be placed on the family structure, considering its strengths as well as its weaknesses. This focus should involve a specification of such factors as the number of family members in the home; ages of children; significant others inside and outside of the home; resources available; patterns of interaction, rule structures, value systems and disciplinary style of parents; and health of members.

After the family structure has been analyzed the effectiveness of the parents' communication, problem solving, and child management skills should be thoroughly assessed. This step is undertaken because it is to the parents that the therapist must look for leadership in resolving family conflicts. Before problem behaviors and situations are targeted and dealt with, it may very well be necessary to first impart problem solving, communication, and child management skills to the parents.

When it may be concluded that the parents possess adequate skill levels in the above described areas the step of pinpointing the problem(s) is taken. This step should include an objective definition of problem behavior(s) within the context of the family structure. In addition to this definition, consideration should be given to the individuals and situations that are contributing to the maintenance of the problem behaviors. Provision should then be made for the observation and recording of the problem behavior(s).

Interventions should be consistent, systematic, and should emphasize positive rather than negative strategies. The aim should be to increase positive and decrease negative situations to meet this end. In some instances it might be possible to reduce interpersonal stress by modifying or clarifying family rule structures or adopting various general behavior management strategies such as point or token systems, etc.; it also might be desirable to implement a more highly individualized intervention for problems that require intensive therapeutic attention.

Finally a potentially effective vehicle or format for not only solving but also preventing family conflict is the family meeting.

III. RECOGNITION OF PSYCHOLOGICAL NEEDS OF HANDICAPPED CHILDREN

John Havertape, Ed. D. Professor, Special Education, University of Nevada Reno
Director of the Special Education Program

It is difficult to condense on a single page one's views on the psychological needs of handicapped children and not appear very narrow in scope. In my view, the psychological needs of exceptional children are like those of all children. Among these are the need for non-conditional acceptance, love and accomplishments which leads to a positive self image and feelings of success and competence.

One particular need that is vital to handicapped children is the honest recognition by the child and parent(s) that he is handicapped and that at least some normal expectations are inappropriate and cannot be met. A great deal of effort, money and time is often spent locating, defining and diagnosing handicaps. Conversely, the unfortunate consequence is to maintain expectations of normalcy. This places a great deal of pressure on parents to demand normal performance, as well as an impossible burden on the child to be what he cannot be. The resultant feelings of inadequacy will undermine any efforts to communicate an acceptance of him as he is or to make him feel successful.

Honesty in recognizing the problem allows the child to accept his deficits without feeling he must cover up his handicap to protect his parents from having to deal with it or disappointing them. Parents often do not discuss the problem frankly, because they don't want the child to feel that he is different. In most cases, however, the mildly handicapped child is painfully aware of his deficiencies almost as soon as his parents.

Failure to be honest and open about the problem then creates an atmosphere that the handicap is something so awful that it cannot be discussed.

If parents are aware of the child's deficits, disabilities and needs, home demands can be modified so that daily living becomes a learning experience for the child. Small adaptations in family demands may mean the difference between a child who feels successful and one who feels defeated. The home demands can then gradually be increased to develop a sense of responsibility and increase his competence.

Some of the modifications and aids parents can make are : use simplified language in giving directions and in conversation; reduce instructions to one or two demands; insure that the child is attending to what is important when you are instructing or demonstrating a skill; provide structure to all activities; organize activities and insist on stepwise solutions to problems to teach problem solving. Parents must recognize impulsive tendencies and attempt to help the child control these, explain consequences of actions, cause and effect relationship of daily occurrences and assist the child to interpret social situations and communications.

Parents must above all recognize their own limitations. There are so many occasions when the handicapped child is hurt by the world and so justifiably angry, and parents are unable to protect the child from hurt or erase it. The pain cannot be taken away, but parents can recognize the child's right to be angry and offer encouragement, support and empathy.

Home must be a refuge for the handicapped child where the demands of the world which buffet him in every other area of life are adapted and modified to his level of competence. It is essential that he be secure in this one sphere to develop those capabilities that he does possess. At home, his achievement must be recognized, encouraged, and measured against his own potential, not others. After all, it is the daily accumulation of small gains which leads to eventual competence.

Jess LaMonda, Ed. D. Executive Director, Eagle Valley Children's Home

POINTS TO BE PRESENTED FOR DISCUSSION:

1. Handicapped children have the same basic psychological needs as normal children, and like normal children, how those needs should be met is a factor related to the child's developmental age or mental maturity.

2. In order for parents (or others) to determine the psychological needs of a child they must have information regarding:
   a) the child's developmental age
   b) his/her personality type, and
   c) the basics of developmental psychology

When there is a wide discrepancy between the child's developmental

age and chronological age, it is advisable for the parents to seek professional assistance and guidance. It is very difficult to keep from being either too demanding or too lenient, thereby inadvertantly placing additional stress on the child and/or family.

3. Handicapped children and their families usually have to endure greater stress than others. Such stress can have a negative effect on all involved unless dealt with constructively. One major source of stress is frequently lack of respite. The non-handicapped family members need some periodic relief to do the things normal families take for granted. If such needs are not met, they tend to get magnified by financial strain, personal fatigue, and other personal and family needs, and resentments (why me?) tend to develop which frequently lead to guilt and other forms of stress.

   The handicapped child's psychological needs cannot be adequately met without the support of a psychologically healthy family. The The needs of all family members must be considered--not just the child's. Adequate respite coupled with professional family counseling could very well be the two most significant factors in meeting the handicapped child's psychological needs.

IV. RECREATIONAL AND LEISURE TIME OPPORTUNITIES

Robert A. Guerrero, Recreation Specialist, Nevada Vocational Rehabilitation

Everyone needs recreation. Not only as a stress release mechanism but to assist in developing appropriate values, self-confidence, self-image, strength, stamina, balance, coordination and social skills.

Handicapped people often need effective recreational experiences more than non-handicapped people because of limited recreational opportunities and often the amount of leisure time available.

Therefore it is essential for support systems of handicapped children to:

a. Understand the necessity of recreational development
b. Develop appropriate leisure attitudes.
c. As a consumer advocate develop resources in the community.
d. Develop persistence.

Resources one can explore are:

a. Mainstream community resources.
b. Join support groups of all types.
c. Subscribe to handicapped publications.

Vocationally speaking it is much easier to assist someone or for someone to secure appropriate and meaningful employment if one has skills in all areas of development.

This is demonstrated by handicapped people all the time.

People are only limited by themselves. Allow and assist a person to explore his/her potential and usually the ability will be carried into all areas of life. Play to live.

The payoff will be the development of normal growth patterns to the individual physically, emotionally, socially and mentally. All these are essential for everyone to have a better opportunity at leading a personally rewarding life.

FILM: "A MATTER OF INCONVENIENCE." Handicapped skiing as a means for the handicapped person to demonstrate that "If I can do this, I can do anything."

PARENTS CAN MAKE A BIG DIFFERENCE!

Allen A. Mori, Ph. D. Professor, University of Nevada Las Vegas

In 1974 in his analysis of preschool programs, Urie Bronfenbrenner noted:

> The involvement of the child's family as an <u>active participant</u> is critical to the success of any intervention program. Without such family involvement, any effect of intervention...appears to erode fairly rapidly once the program ends. In contrast, the involvement of the <u>parents as partners</u> in the enterprise provides an ongoing system which can reinforce the effects of the program while it is in operation, and help to sustain them after the program ends (p. 55 - emphasis added).

Since we can now document that effective parent-child interactions can lead to increased child performance, and that parents will become involved in intervention programs for their children provided the level of involvement is appropriate (Karnes, 1973), it is then important to provide some guidelines to build constructive, cooperative parent-professional relationships.

- Establish good lines of communication
- Organize the program to insure that parents are active participants in all facets of the program, including decision-making.
- Design the program to include support services for families that experience problems and frustrations coping with raising a handicapped child.
- Individualize the entire intervention strategy for families involved in the program.
- Recognize and use a family's strengths in the conduct of the intervention program.
- Parent education or training must be based upon a family's needs and provided at a level that is within that family's capacity to respond.*

Working cooperatively in an atmosphere of mutual trust and respect forges a cornerstone for meaningful parent-professional relationships that insure the optimum development of all young handicapped children.*

References

Bronfenbrenner, V. Longitudinal Evaluations: A Report on Longitudinal Evaluations of Preschool Programs, Vol. 2: Is Early Intervention Effective? (Pub. No. OHD 74-25). Washington, D. C.: Department of Health, Education and Welfare, 1974.

Karnes, M.B. Payoff of Early Intervention. Chicago: Council for Children with Learning Disabilities, 1973.

*All materials from this summary adapted from Dil and Mori, A Guide for Training Families of Young Children with Special Needs. Aspen Systems Corporation, in preparation.

OPERATION COPE! COPING SKILLS FOR EFFECTIVE PARENTING

Vince Triggs, Director, Southern Nevada Association for the Handicapped (STEP) PROJECT

Southern Nevada Association for the Handicapped has been awarded a grant from the U. S. Department of Education to conduct a parent advocacy training program for parents of the handicapped, interested professionals and other concerned citizens. The purpose of the Specially Trained Effective Parents (STEP) Project is to train parents to become independent life-long advocates for their handicapped children, helping to assure a positive response within the community to the rights of the handicapped as guaranteed under federal and state statutes and case law.

The five "steps" of the STEP Project will lead parents from basic awareness through a series of workshops, seminars and practical involvement to a level of independent, constructive and cooperative advocacy for their handicapped children. Close cooperation with community agencies, local schools and state personnel will help to develop a climate of cooperative interaction toward the common goal of better, more effective, free and appropriate educational and related services to the handicapped. At each "step" of the training project, support and consultation will be available from the professional STEP staff.

In a time of tight money and budget cuts, the need will be greater than ever for an active body of well informed, cooperative and positive parent advocates for the handicapped. This need also conforms to the basic philosophy of SNAH that a handicapped child's first and best advocates are his parents.

Child care will be available at all STEP activities. Or, if parents prefer, they can be reimbursed for their own child care expenses. In addition, mileage reimbursement is available for STEP participants travelling 25 miles or more round trip.

The Southern Nevada Association for the Handicapped is one of only fifteen community parent organizations nationwide to be awarded a parent advocacy training grant by the Department of Education.

VISUAL IMPAIRMENT, LOW VISION, PARTIALLY SIGHTED

Richard F. Meier O.D. Doctor of Optometry

Many children in America have vision difficulties. The most easily detected ard diagnosed of these deals with dimished sight. Myopia, astigmatia, and hyperopia can usually be compensated with standard lenses. However, some children have congenital cataracts, retinitis pigmentosa, diabetic retinopathy, macular degeneration, and the list goes on. These diseases usually can not be remediated with standard lenses or even surgery (except for cataracts;) unfortunately the parents of these children are usually told nothing can be done. Perhaps the problems cannot be cured, but much can be done to assist these individuals in leading a more productive life if there is partial sight. With the use of bioptic lenses, telescopes and microscopes, most can move around in their world with much more ease and independence. There are many low vision aides available today; the new honeybee bioptic telescope lenses developed by Dr. Feinbloom have been receiving a great deal of publicity recently. The State of Nevada will now license individuals who use telescopes to operate motor vehicles.

Another area of vision that is not being diagnosed and treated is the way in which an individual uses his or her eyes during the reading process. It has been estimated the 75 to 95% of all classroom learning comes to the student via visual pathways. The skills necessary for reading are the ability to track along a line of print, to proceed from the end of a line to the start of the next line, to sustain a focus, and to keep the letter single. It should be stated that vision and acuity are not synonymous. Vision is a learned skill whereas acuity measure the "sharpness" of sight. Vision, then, is an ability to understand not only sharpness of detail, but relationships. After a vision dysfunction has been diagnosed, optometric treatment may include the use of lenses, prisms, visual training programs, developmental vision guidance, and low vision programs.

CLOSING REMARKS

Ted Sanders, Nevada Superintendent of Public Instruction

The Nevada State Board of Education and the Nevada Department of Education have historically been and continue to be committed to the development and maintenance of high quality educational programs for handicapped students. We also recognize parents as the child's first and primary teachers and strongly support parent involvement in their children's programs. Research also indicates that children's greatest gains are made when parents are involved.

Congress recognized the value of parent involvement with the passage of Public Law 94-142. Current regulations for that law require parental consent for evaluation and placement, parent participation in the

development of Individualized Education Programs, and parent rights to due process.

Just as children exhibit readiness to learn certain skills at certain times, parents also can be seen at different readiness levels for involvement in special education programs. Our job as parents and professionals is to accept, support and encourage parents at all levels and provide an environment that promotes growth in parents, just as we do for children.

To that end, the Department of Education is ready to meet with parents to explore and promote the improvement of special education programs as well as parent involvement in those programs. We are accessible and committed to maintaining and improving educational programs for handicapped children and their families.

PARTIAL LIST OF EXHIBITORS

CHANCE - Coalition for Handicapped Children's Education
Eagle Valley Children's Home
Governor's Committee on Employment of the Handicapped
Richard F. Meier O.D. Doctor of Optometry
Nevada Association for Children with Impaired Hearing
Nevada State Library
Northern Nevada Chapter Medic Alert
Northern Nevada Epilepsy League
Northern Nevada Association for the Handicapped
State of Nevada Rehabilitation Division
Tahoe Handicapped Ski School
Social Effectiveness Training Project
Guide Dogs for the Blind, Inc.
Eyes for Tomorrow 4 H Club
Association for Retarded Citizens, Inc.
Abbey Medical
Northern Nevada Mental Retardation Services
Child Find Project, Special Education Services, Washoe County School District
National Federation of the Blind
Sierra Developmental Center
National Academy for Child Development
Southern Nevada Association for the Handicapped

The Northern Nevada Directory of Handicapped Services is available through the Office of the Governor's Committee on Employment of the Handicapped, 505 East King Street, State Capitol Complex, Carson City, NV 89710 (702)885-4440. Kathleen Olson, Executive Director.

WE CAN DO IT TOGETHER! EVALUATION AND PARENT SUGGESTIONS

Adele Somers, Ed. D. Community Development Consultant
Continuing Education, University of Nevada Reno

The successful and significant conference, WE CAN DO IT TOGETHER!, was attended by parents and others interested in services for the disabled child. They were most appreciative of the expertise and information they received. The following comments were expressed by the participants:

Would like another conference.
Would be happy to attend more conferences.
More-more-more. Let's have another one!
More! Appreciated the time taken by very qualified people to share information and experience. Thoroughly worthwhile!

A parent of a child with a disability advises, "Parents need lots of determination, strength, love, and patience. Be your child's greatest support. Don't give up from one resource. Try another resource and find alternatives. Get together with other parents. We think we are only one little voice but when we get together we have PARENT POWER."

Goldie Zacks, a close friend, was stricken with polio as a young child. She offers the following suggestions to parents:

"Parents should accept the child with loving attention and understanding. No pity should be shown in any situation. Be aware of and acknowledge the child's limitations. However, do not stress or dwell on it with the child.

There should be bountiful amount of encouragement on what a child decides to do. The understanding is that the child might fail. Even though failure may occur the first time, the child should be encouraged to try again. When a goal is set, the child should be aware of the various ways to reach the goal. A child should be informed, "If you need help, we're here." Parents should work with a degree of accomplishment when a child finally learns to do a task. It can be exasperating to watch the procedure by a sibling or parent. It takes patience. Try not to take over and do the job. Create an air of independence. "Let me do it for you," can be annoying for the normal child and devastating for the child with a disability. The disability can be minimized with training. Be sympathetic, and be there to teach and encourage.

Parents can introduce the children to peers, and encourage them to play together. Often the child is overprotected and overrejected. Make the healthy child aware of the child with a disability. It is better for children to be among peers who are not handicapped. Kids get exposure to people who are not kind. You've got to learn that you will not be accepted by everybody. Children with disabilities should be allowed to go to the regular school. Then the kids begin to help each other."

Parent seminars and parent support groups with professionals can encourage and support parents. WE CAN DO IT TOGETHER!